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Article (Accepted Version)

Bailey, Ruth, Lowton, Karen and Scambler, Sasha (2019) Threats to embodied well-being: An exploration of how disabled people negotiate barriers in hospital settings. Health. ISSN 1363-4593

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# **Threats to embodied well-being: An exploration of how disabled people negotiate barriers in hospital settings**

**Ruth Bailey, Karen Lowton, Sasha Scambler**

## **Abstract**

Taking a social model of disability approach, this article explores how disabled people negotiate barriers in the large, modern hospital settings typically found in complex healthcare systems. While there is evidence of intractable barriers in the United Kingdom's National Health Service, little is known about the actions disabled people take in the face of barriers and the immediate effects of doing so. Analysis of data from a qualitative study of disabled people's healthcare encounters is presented. This draws on the concept of threats to embodied well-being to understand how disabled people perceive barriers and the influence this perception has on barrier negotiation. It demonstrates that some barriers are unique to healthcare and that these place disabled people in situations where their well-being is threatened. Despite these situations being inherently disempowering, disabled people are forced to take whatever action they can to protect the embodied self. We theorise that barriers are created inadvertently by the design, organisation and healthcare practices characteristics of modern hospital settings. Effective barrier removal requires understanding not only their impact on disabled people's embodied well-being, but also the political, policy and social relations implicated in their creation.

## **Keywords**

disabled people, disabling barriers, embodied well-being, healthcare services, qualitative, threats, UK

## **Introduction**

In the United Kingdom, disabled people face a range of barriers – such as inaccessible buildings or a lack of disabled car parking spaces – when using the National Health Service (NHS), causing dissatisfaction, and potentially deterring health service use itself (see, for example, Allerton and Emerson, 2012; Lawler et al., 2013). According to the 2011 World Report on Disability, these barriers deny and/or discriminate against disabled people when trying to access healthcare (Shakespeare, 2012) and appear to be common across all developed healthcare systems (Van Doorslaer et al., 2000). Here, the meaning of barriers is derived from the social model of disability, where it denotes any feature of the material, social or cultural world that excludes or discriminates against a disabled person (Oliver, 1990). This approach understands a person's impairment as a bodily difference, with disability arising from a social environment regardless of the extent or nature of bodily difference. Disabilities are thus socially created and not dependent on the individual's type or location of impairment. In this model, naming something as a barrier is a demand for its removal or the mitigation of its adverse effects. Nonetheless health policy often overlooks disability (Paudel et al., 2016), even in countries where healthcare providers are bound by equality and anti-discrimination legislation. This is the case in the United Kingdom,

where the NHS has a duty to design and deliver barrier-free healthcare as well as the improvement of disabled people's health outcomes (Imrie and Luck, 2014). The NHS must achieve this by making what are known as 'reasonable adjustments'. This means a change must be made to any feature of a building, practice or policy that would otherwise cause a disabled person to be treated unfairly or less favourably than other patients.

Building on a social model of disability approach, we aim to provide theoretical insights into barriers created inadvertently by the features of large, modern hospital settings in complex healthcare systems. The focus here is on the social construction of barriers related to mobility at the micro level. More particularly, we explore how disabled people perceive and negotiate barriers in NHS hospital settings and what effect this has on their embodied well-being.

Work at the macro level has explored the types of healthcare barriers people with impairments face and the longer-term consequences of these, such as a lack of accessible information serving to increase the risk of developing further potentially preventable health conditions (Allerton and Emerson, 2012; Shakespeare et al., 2009). However, comparatively less work has focused on the micro level, for example, upon the immediate actions people with physical impairments take when confronting a barrier and the more immediate adverse effects of this. As Winance (2014) argues, effective barrier removal at the macro level must be complemented by enabling environments and practices at the micro level which can accommodate the diverse and sometimes unique needs of disabled individuals. To explore this micro level, data were used from a qualitative research project that investigated disabled people's healthcare encounters. As the research was exploratory, the data were restricted to that which described environmental barriers associated with mobility impairments. In keeping with our social model approach, when drawing out factors implicated in barrier creation priority was given to those related to the social environment over those related to individual bodily difference.

When analysing this data, the concept of threats to embodied well-being was devised to throw light on how both the anticipated and real consequences of barriers might influence the way they are negotiated. This analysis drew on three conceptual strands of work: first, the on-going monitoring of physiological processes as potential threats to corporeal and embodied well-being (for example, Robertson, 2006); second, threats to bodily integrity brought about by movement through potentially dangerous public spaces (for example, Imrie, 2012); and third, threats to the self that arise from these situations through felt and enacted stigma, shame and blame (Scambler, 2009). These concepts exposed interactions between bodies, spaces and practices enabling identification of factors within the hospital environment which shape the embodied experience of negotiating barriers. While acknowledging that bodily difference and biography also contribute to embodied experience of barriers, our social model approach underpinned the decision to focus on social factors. We consider here how these threats can be understood in the process of disabled people's negotiation of barriers in a hospital environment. To provide context to our analysis, we first overview briefly debates about the negotiation of barriers in general and in healthcare in particular.

## **Negotiating barriers**

Barriers take multiple forms, which can be categorised as environmental (here we focus particularly on the use of space, such as inaccessible buildings and services), organisational (particularly inflexible policies, practices and procedures), and social (including the emotional effects arising from stereotyping, discrimination and prejudice) (World Health Organization (WHO), 2001). Negotiating barriers refers to the measures a disabled person takes to avoid a barrier or to mitigate its effects. It is difficult to specify exactly what actions constitute 'negotiations', as these will depend on the nature of the person's impairment and the nature of the barrier encountered, but these could incorporate telephoning ahead to ensure the availability of specialised equipment such as hoists, or allowing extra time to travel to appointments. When a disabled person encounters a barrier, its details and effects are contingent upon the interplay between three factors: the embodied experience of the disabled person, which includes impairment but is rarely reducible to it; the characteristics of space and its related practices; and the acts or omissions of others. The site of that interplay is embodiment, which comprises the physical, emotional and cognitive capacities as shaped by and interpreted through all prior engagements with the world (Turner, 2004). The aspect of that interplay foregrounded in explanations of barriers is that between impairment and place (Crooks and Chouinard, 2006). More recently, geographers have argued that space is constituted by a web of social relations always in the making (Massey, cited in Hall and Wilton, 2016). From this perspective, the interplays between bodies, objects, practices and spaces always 'have the capacity to produce both exclusionary and/or enabling arrangements' (Hall and Wilton, 2016: 2). Even though many barriers have a material form that cannot always be removed in real time, how disabled people and healthcare professionals perform and interact shape how any particular healthcare encounter is experienced and its outcome.

It is through embodied experience that impairment influences engagement with the world, for example, a visual impairment can result in navigating through public space using a white cane, not (primarily) the eyes. Similarly, the moment-by-moment experience of impairment influences how a space is experienced; being fatigued can make a crowded waiting room an uncomfortable place. Impairment, then, is one aspect of embodiment that influences both what has to be negotiated and the capacity to negotiate. But negotiations are also influenced, and in many instances made necessary by, the actions of others or the characteristics of a place, such as steps that prevent a wheelchair user entering a building. More insidiously, for a disabled person, a healthcare appointment can be made more stressful by the cumulative effects of barriers which by themselves have a relatively minor impact, such as a heavy entrance door or a healthcare professional displaying signs of discomfort upon first meeting (Hansen and Philo, 2007). Any barrier is a potent reminder that disabled people are always excludable, as inclusion is always conditional on someone else's perception of who belongs where (Titchkosky, 2011).

It has been recognised that the ability to negotiate barriers requires skill, energy and resilience and is influenced by the disabled person's socioeconomic position (Allen, 2004). Furthermore, negotiations often involve a number of tasks that can become burdensome and cause treatment delays. For example, an invitation for breast screening would require a non-disabled woman to make minimal arrangements, all done in a taken-for-granted manner. By contrast, a disabled woman might check accessibility, make transport arrangements or talk through the procedure with a healthcare professional to attempt to identify potential barriers and assess whether

they will undermine the efficacy of the screening procedure. All this can deter attendance at non-emergency healthcare appointments, which contributes to greater inequalities between disabled and non-disabled people (Mele et al., 2005). However, whatever actions a disabled person takes, whether he or she succeeds in mitigating the effects of a barrier always depends upon the actions of someone else due to the power differential between disabled and non-disabled people which is at the core of every barrier (Scully, 2010; Thomas, 1999). This power differential is then magnified in health service use by the power imbalance between the healthcare professional and patient (Angus et al., 2012). The literature suggests then that for disabled people, perceiving, experiencing and negotiating barriers is a multi-layered process, the outcome of which is always dependent upon others.

### **Negotiating barriers in healthcare settings**

The environment and practices of healthcare reflect the normative purpose of medicine: to restore health to the sick body (Gesler et al., 2004). While this is lauded by most, including disabled people, it implies that there are just two bodily states, sickness and health. In this binary, there is no acknowledgement of impairment shaping a distinctive bodily state whose attributes need to be incorporated into the range of bodily norms that underpin the design and delivery of healthcare. This appears to have resulted in the NHS struggling to recognise or respond to disabled people's needs (Abraham, 2011) and raises the question of what influence this has on a disabled person's need to negotiate barriers in the NHS and the options available to do so.

McFarlane (2004) explored the experience of disabled women who had used the Scottish NHS reproductive services in Edinburgh and Glasgow. One of her key findings was that women were often made to feel unexpected and unwelcomed. This was due to barriers whose roots were traced to three factors: the cultural norms that consider disabled people as asexual and removed from family life; the design and delivery of reproductive services; and the perception of healthcare professionals. In this context, McFarlane demonstrated that what disabled women experienced as barrier negotiation was often understood by healthcare professionals to be breaches of protocols or disruptions to institutional practices. For example, a nurse publicly chastised one visually impaired woman for changing her baby on the bed because, for safety reasons, hospital protocols required babies to be changed in the crib. This mother found it easier and safer to change the baby on the bed, negotiating a protocol designed for a sighted mother, but was perceived by a nurse to be putting the baby at risk of falling. Not only do such conflicting perceptions act as a dynamic in the process of negotiation, they also mar the relationships between the women and healthcare professionals. What McFarlane (2004) demonstrates then is that often in hospitals the negotiation of barriers is much more complex than problem solving due to the underlying normative structures and the challenges these pose to disabled people. More recent studies shows healthcare professionals are themselves aware of this complexity. For example, a study of UK manual handling policies found nurses perceived various tensions, including between using hoists to protect their own health and encouraging patients to be as mobile as possible (Kneafsey et al., 2013)

Another strand of research on the negotiation of barriers in healthcare settings focuses upon the material body and its interaction with imaging technology. Although such technology bears the material imprint of the normative body it also demands

much of the sick body. The healthcare professional therefore acts as an intermediary to secure patient compliance, such as tolerating an uncomfortable position or remaining still (Poulos and Llewellyn, 2005). This can result in being 'pushed beyond limits', where a healthcare professional unintentionally manipulates the body in a way the disabled person experiences as intolerable (Hassouneh-Phillips et al., 2005). It is as if the professional gaze fails to register embodied difference and the need to adjust practice accordingly. This failure itself has to be negotiated, requiring the disabled person to assert their difference and its implications in the current context. This is not easy, but it can enable the healthcare professional to foster a collaborative relationship, acting upon the patient's experience of their body to find a way to minimise discomfort but maximise the effectiveness of the test or procedure. However, research suggests that some professionals discount the disabled person's expertise of the body, which can be harmful physically and emotionally (Hassouneh-Phillips et al., 2005; Lawler et al., 2013).

What these studies show is how the design of hospitals and the practices of the professional within them disregard embodied differences. This has not been fully explored in the literature, even though health policies encourage service providers to seek out and listen to the voices of disadvantaged sub-populations including those of disabled people (see, for example, NHS England, 2013). There is also little said about the detail of how disabled people decide upon the actions available to negotiate a specific barrier. Similarly, the implications of these negotiations upon the immediate well-being of the embodied self are not considered. This is something the research described below sought to address.

## **Methods**

This article draws upon qualitative data generated by a study of disabled people's healthcare encounters. One aim of the study was to understand the barriers disabled people experience in healthcare. To address the gap in existing research, the focus was on how disabled people both identified and negotiated barriers. The following research questions were therefore devised:

**Research Question 1:** What barriers do disabled people face when using the NHS?

**Research Question 2:** How do disabled people negotiate barriers?

**Research Question 3:** What are the consequences of negotiating barriers?

As the study was exploratory, data were generated through semi-structured interviews using a topic guide. With regard to negotiating barriers, all participants were asked the simple question: Have you ever encountered any barriers when using the NHS? This question followed the social model approach to disability by not specifying or prescribing what constitutes a barrier; rather it was anything that the participant perceived it to be. Of course, not all disabled people interpret their experience of the world using the concept of barriers. Therefore, prompts were used to invite participants to talk about (non-clinical) 'problems' during the course of a healthcare appointment or hospital stay, as well as asking directly if they had encountered certain types of barriers, such as the attitudes of healthcare professionals. The aim was to encourage participants to give a detailed account of encountering a barrier and to offer their reflections upon it.

To devise a strategy to recruit participants, criteria for determining disability status were needed. One approach was to use a proxy measure, such as eligibility for Disability Living Allowance or entitlement to legal protection from disability discrimination. However, this would have required the researcher to request verification, posing ethical issues such as whether to recruit someone who 'appeared' to the researcher to have an impairment but who had no 'proof' of disability status. Hence the social model perspective was adopted, which disregards the specific impairment a person has and instead foregrounds self-identified barriers to full social participation. It follows from this that participants were not asked directly about the nature of impairment or the circumstances of its onset. Although this information was often disclosed or apparent from descriptions of healthcare encounters, no inference was drawn from this in the analysis due to the risk of misassumptions and the decision to focus upon barriers. As well as being pragmatic, this fitted the study aim of exploring how a person used the category 'disability' to interpret their experiences of healthcare. There are of course pitfalls with using a self-definition: a person could self-identify as having a chronic illness or impairment but not as disabled, or someone may self-identify as disabled but not (yet) be regarded as such by others. These points have been helpfully expanded upon by Grue (2016), who notes that 'it is possible for a person to be disabled without recognising themselves as such ... (and) for a person to be disabled without being recognised as such by others' (p. 959). However, a participant in either situation could provide insights into the constructed and contested nature of the categories of impairment, disability and chronic illness and how they influence the experience of healthcare.

In addition to self-identification as disabled, three other criteria for inclusion in the study were used: having a physical impairment; living in Edinburgh and the Lothians; and being aged between 18 and 65 years. These reflected the client group served by ECAS (not an acronym), a local disability organisation that funded the research, and were specific requirements of the funders. To recruit eligible participants, contact was made with impairment-specific groups. An advertisement was also placed in the local paper in an attempt to recruit people not part of established networks. As recruitment was slow, participants were asked to pass on study information to anyone who might want to contribute. In total, 27 physically impaired people were recruited, three of whom also identified as having a learning difficulty and five of whom made reference to mental health problems.

Interviews were limited to 1 hour to accommodate the limited energy levels of the interviewer (author 1) and to enable participants to pre-arrange transport and assistance. Fearing this would compromise data depth, each participant was invited for two interviews; only two declined, feeling everything necessary had been said. The second interview was structured around a summary of the first interview, produced from the field notes and audio recording. It highlighted the main narrative thread of the interview and the experiences judged to be of most significance to the research. Each participant was sent the summary and then invited to comment upon its accuracy and representation of what they wanted to share. With the research aims in mind, the interviewer also asked any follow up questions necessary to gain further detail or explanation of experiences previously described. All interviews were transcribed and to ensure anonymity participants were given pseudonyms with personal details changed wherever necessary.

## Analysis

This article draws upon data generated in response to the questions on barriers. Analysis proceeded by assigning each section of the data to the research question it could help to answer. Hence the codes used were: 'perceived nature of barrier'; 'negotiating the barrier'; and 'consequences of barriers'. A subsequent interpretative reading suggested further analysis was needed to conceptualise the process of negotiating these barriers and what was unique about barriers in healthcare.

The concept of threats to embodied well-being was used to analyse how barriers are negotiated. The roots of this concept lay in the data coded 'consequences of barriers' because they contained descriptions of anticipated consequences of barriers, which often triggered the process of negotiation. Mindful of Imrie's (2012) concept of threats to embodied integrity, and the concept of felt stigma (Scambler, 2009), this anticipation had the quality of a threat; namely that it causes a reaction irrespective of whether it is subsequently realised. This would result, for example, in a participant making alternative transport arrangements to a hospital appointment rather than risk driving and being unable to park at a manageable distance from the entrance. Hence, even when a barrier was avoided by negotiations, it still resulted in disadvantage, albeit one the participant considered less significant. It is important to note that the concept of threats was used to analyse barriers related to mobility, although economic and attitudinal barriers were also described by the four participants identified as having both physical and learning difficulty (Bailey, 2009).

Having identified examples of barriers perceived as a threat, attention turned to analysing exactly what a barrier threatened. It is recognised that barriers have multiple wide-ranging consequences encompassing social, psychological, physical and economic issues (Neri and Kroll, 2003) but little has been said about the more immediate effects on well-being, despite such effects often featuring in disabled people's accounts. These effects might include, for example, the pain of being transferred from one location to another, such as being lifted from a wheelchair to the optician's examination chair. Negotiation can also demand emotional labour (Hochschild, 1983), such as working to maintain a particular self-image when enlisting the assistance of others. Moreover, the disabled person who negotiates barriers is an embodied agent whose actions are derived from previous experiences of negotiations as well as socioeconomic position. These examples illustrate the threats to embodied well-being from encountering and negotiating barriers, underlining the fact that a disabled person's sense of being healthy may be jeopardised by barriers themselves and not (just) impairment.

The analysis is presented by means of four scenarios. This format is chosen as it makes it possible to first explore in detail the participant's perception of the barrier and then to trace back the influence of context. In selecting which of the participants' experiences to construct as scenarios, the main criterion was that it illustrated the utility of the concept of threats to understand the process of negotiating barriers unique to healthcare. Within that, these four were chosen as they demonstrate four types of barriers, each unique to healthcare and each recounted by participants with different experiences of physical impairment. Although they are indicative of a diversity and range of experiences, rather than representative of all the barriers identified by the research, they illustrate the three types of barrier outlined above (social, organisational, and environmental), and the ways in which they intersect.



## **Scenario 1: the threat of breathlessness**

This scenario illustrates a barrier rooted in the scale of modern hospitals, which threatens physical well-being through the use of spaces within the hospital. It draws on the experience of Betty, a middle-aged woman with an autoimmune disease, which necessitated regular attendance at the respiratory clinic. Before each visit, Betty faced the threat of acute breathlessness, induced by the walking distance between the hospital entrance and the clinic. When realised, this threat caused embodied distress and impaired speech, making it difficult for Betty to communicate with the consultant.

To negotiate the distance barrier, the only option was to enlist the assistance of others. Betty would establish a rapport with the ambulance personnel who provided her transport, to persuade them to wheel her to the clinic, thus mitigating the effects of the barrier. While the personnel were usually willing, their work schedule did not always allow this and the availability of a hospital wheelchair was never guaranteed. This ad hoc arrangement magnified the threat Betty experienced. It could also be seen as symbolic of an indifference to Betty's well-being, especially as formalising the arrangement with the ambulance service would have been a contribution to the hospital's compliance with equality legislation.

To contextualise the distance barrier, two issues need examination. The first concerns the meanings and priorities of movement around the hospital, something symbolised by the purpose and availability of wheelchairs. It can be argued that healthcare professionals perceive a wheelchair as minimising disruptions to caring routines: it speeds up the movement of those whose illnesses have reduced walking speed and affords control over those whose movement is deemed to need medical supervision. This is reflected in the design of hospital wheelchairs, which prevents propulsion by the occupant and favours the accommodation of a diversity of body shapes and sizes over the sitter's comfort. To Betty, however, a wheelchair promised effortless movement through hospital space. The failure to guarantee Betty a wheelchair could be attributed to her outpatient status. As an inpatient, a wheelchair would have been seen necessary to speed up her mobility, as a hospital employee, a power wheelchair might have been provided through the Government Access to Work scheme, but wheelchairs are not routinely provided by the hospital for outpatient appointments. Hence the responsibility for avoiding the threat to embodied well-being posed by distance falls to the outpatient. Avoiding the threat was not possible for Betty, who had no family nearby to assist with hospital visits and lacked the economic resources to purchase a wheelchair. Hence inequalities compound barriers. The second issue underpinning the distance barrier was the privileging of the normative body and medical interests. Betty commented that those designing the new hospital 'didn't have any idea [of the effects of chronic breathlessness]. Sure sign they are OK'. This points to architectural practices which foreground the normative body, which is then mediated by medical hierarchies and health policy (Gesler et al., 2004); hence different interpretations of the body are assigned to different spaces. For example, the clinic room Betty used was probably designed to accommodate the medical gaze directed towards the respiratory tract. However, the mode of movement of the body being gazed upon was not considered in the design of space beyond the clinic door.

In this scenario, the notion of threats captured first, how spatial arrangements in modern hospitals can adversely affect the impaired body and second, the anxiety caused as a result. Betty had to continually confront these threats, as her socioeconomic and family situation rendered her unable to negotiate them in any meaningful way. At the time, the hospital took no responsibility for mitigating the effects of the distance barrier. More recently, some hospitals have followed the lead of other large public buildings by offering mobility scooters for hire (Belfast Health and Social Care Trust, n.d.; Disabilities Fife, 2012). However, they have not gone as far as mainline train stations and airports, which provide a designated service for customers with mobility impairments.

### **Scenario 2: threat to sense of self**

In the next scenario, the barrier remains rooted in the scale and regulation of space within a hospital yet brings to the fore the difficulties this presents to locating and reaching public toilets. It concerns Elspeth, a middle-aged woman with an adult onset neurological condition. When attending a hospital outpatient appointment necessitated a long wait, Elspeth needed to use the toilet. The first threat this posed was to her sense of self, due to the anticipated consequences of failing to find the nearest toilet quickly enough in a large, unfamiliar building. This threat is not confined to disabled people, but what makes it a barrier for Elspeth is her slow walking speed and urinary urgency.

To negotiate this barrier, Elspeth stated her preference was to ask the clinic nurse for permission to use the toilets designated for staff because they were closest. This would reduce the threat of loss of bladder control. However, to negotiate in this relational way posed what Elspeth felt was a greater threat to self, experiencing disability prejudice. To legitimate her request, Elspeth felt an obligation to reveal her disability status, something not visible to strangers. The anticipated consequence of this was emotional discomfort: 'the look in people's faces ... or. 'Oh I am really sorry' ... said in a nice big loud voice'. Of course, the responses might have been supportive. Nonetheless, this felt stigma was sufficient for Elspeth to abandon her preferred means of negotiating hospital space, instead enduring the threat of embarrassment associated with urinating in public.

Here identifying how Elspeth perceived the threats gave insight into her inner dialogue and its role in the negotiation of space. To contextualise this disability prejudice Elspeth imputed to the clinic nurse is perhaps a reflection of its pervasiveness. Similarly, the fear of revealing disability status is an instance of the pressure to conceal impairment (Hughes, 2012). Compounding this, features of the hospital environment may have induced feelings of insecurity and difficulties with the navigation of space: for example, insufficient toilets, appointments overrunning and the tight regulation of the use of space within the hospital building. In this scenario there were two threats; one from the responses of others were disability status to be revealed and the second from urination in what is considered the 'wrong space'. Negotiating these involves the self-reflecting upon which threat to avoid and then dealing with the consequences of the other. What makes this barrier particular to healthcare is that the hospital environment makes some body management tasks more complex; for example, unpredictable waiting times and the distances that must be covered to reach the toilet make managing toilet visits difficult.

### **Scenario 3: threat of falling**

The third scenario illustrates a particular type of barrier located in time and space; those that occur during a clinical procedure or diagnostic test. David, a middle-aged man with a lifelong neurological condition resulting in involuntary movement, described such a barrier. Immediately prior to an operation, David was placed upon a hard, narrow table. This exacerbated his involuntary movement, causing his right arm to 'shoot off' the table edge inducing a threat of falling, and hence to the embodied self.

There are several characteristics of a clinical barrier that make them very difficult to negotiate. One such difficulty is the uncertainty of not knowing in detail what will be done to and/or with the body. This makes it difficult for a disabled person to anticipate the extent to which impairment might make it hard to comply with what will be demanded of the body by the test or procedure. Similarly, healthcare professionals often lack knowledge of how a particular impairment influences a particular patient, making it equally difficult for staff to predict barriers. This was the situation David was in, made worse because the uncertainty made him anxious. In turn, the anxiety exacerbated his uncontrolled movement and made speaking more difficult. Nonetheless, to prevent his body from falling from the table David managed to request that the nurse secured his arm, thereby dealing with the barrier of 'not being able to lie flat on a table of that width'. This request was the only act of negotiation possible for David. He carried out the act, despite fearing it would be interpreted as a 'baby's "I'm scared, hold me" kind of thing'. Hence David experienced a second threat: the denial of his adult personhood. What is noteworthy is that both Elspeth and David anticipated that the way a healthcare professional would respond to a request for assistance dealing with one threat, would lead to another.

Clinical barriers are seldom mentioned in the UK literature, which makes it difficult to assess the scale of the problems and the effects they may have on treatment outcomes. Indeed, data collection is difficult because the category of 'disabled person' is rarely used in clinical settings. In terms of the wider context of these barriers, two factors need considering. The first is that medical paraphernalia and technology always bears the imprint of the normative body. The challenge then, is to encourage the design of medical equipment that is flexible enough to accommodate all body types. In the United States, legislation requires all medical diagnostic equipment to be accessible, yet what constitutes accessibility is poorly understood and context dependent (Lagu et al., 2014; Pharr, 2013). The second factor is that the actions and responses of healthcare professionals make the difference between a good and bad experience.

### **Scenario 4: threat of frustration**

The final scenario, was described by Iris, a professional woman who had recently had a traumatic spinal injury that still necessitated regular appointments. Her account concerns a barrier related to equipment availability and the emotional effects of managing its location or absence, which threatens both frustration due to a delayed appointment and harm from being moved in a non-preferred way. In some circumstances, negotiating barriers requires the disabled person to persuade others to do things to avoid them being excluded. Experience had taught Iris to telephone to check the availability of a hoist before attending any appointment unless it was at the spinal injury clinic. Despite phoning ahead, on several occasions a hoist was not

available. Thus, the threat of a wasted appointment was realised, along with the threat to sense of self: Iris commented 'I could see that they weren't expecting me to be in a wheelchair', suggesting she felt 'out of place'.

To put the equipment barrier in context, the main factor is the asymmetry of power. This asymmetry is not only between healthcare professional and patient, but also between anyone connected by proximity or role to a barrier and the disabled person whose intentions are being thwarted by that barrier. In short, whatever negotiations Iris undertook, it was not within her agency to ensure the availability of the hoist. Hoists are (still) not routinely available, so by default Iris has the responsibility to ensure one is available, but without the power to do so. Underpinning this is a disparity in provision between disabled and non-disabled people. For example, most examination tables in imaging departments are height adjustable or steps are provided. A hoist serves the equivalent function for a wheelchair user. As Titchkosky (2007) argues, the underlying issue is the perception of who belongs and is therefore accommodated, and who is always excludable.

Hence in making the call to request the hoist, Iris assumes responsibility for what is provided for other patients as a matter of course. As with wheelchairs, the distributions of hoists within a hospital reflects the priorities of healthcare professionals; for example, wards usually have hoists as professionals regularly need to lift inpatients, but not so in outpatients or diagnostic centres, where the patient is the one disadvantaged if an appointment has to be rescheduled due to its absence. Yet the responsibility Iris was forced to assume is not backed by power. When a disabled person attempts to negotiate a barrier, they do so from a position of disempowerment. However effective Iris' embodied agency might be, hoist availability is ultimately dependent upon others, especially in the absence of procedures for documenting and fulfilling requests.

## **Summary of findings**

Hospital barriers need to be understood as complex intersecting networks of social, organisational and environmental factors that intertwine in challenging the non-normative body. This necessitates disabled people negotiating barriers that exist on both distal and medial levels. Our findings confirm that some of the barriers disabled people face remain unique to healthcare. What makes them so is the design and control of healthcare spaces, the clinical practices done to the body, and the power differential between healthcare professionals and patients. Barriers often placed participants in situations where immediate well-being was under threat. Sometimes these threats were realised, for example, through a lack of available wheelchairs resulting in Betty arriving at her appointment acutely breathless and with impaired speech. However, whether realised or not, threats mediate the experience of relationships and space, a point made by the participant who reported continuously looking over her shoulder fearing being challenged for using her scooter inside the hospital.

For each scenario described, participants expended effort to negotiate the barriers in a bid to protect their embodied well-being. These efforts took many forms, including the development of a collaborative relationship with a healthcare professional to persuade them to adjust their practices. In a sense then, the negotiation of barriers

requires an assertion or demand for change yet requires the disabled user to take responsibility for weaknesses in NHS provision. When this goes unrecognised, it is a cause of frustration and an invalidation of disabled people's everyday experience.

These findings indicate a need for greater understanding of the effects of barriers in hospital settings on equality of access to appropriate healthcare and ultimately on equity of health outcomes. Data are needed that explore relationships between a disabled person's ability to negotiate barriers and biographical and socioeconomic characteristics. Similarly, there is scope for micro level investigation of how particular barriers are related to specific characteristics of a hospital environment, such as type of provider, design and management of the estate and the population it serves. More immediately, while each scenario focused upon the experience of one individual, each barrier was contextualised to suggest ways it may relate to the design and practices common to modern hospitals in other complex healthcare systems. Consequently, our findings contribute to theoretical debates about the inadvertent creation of barriers.

## **Discussion**

Historically, academic study of disabled people and their use of and movement around a social environment has progressed separately to the sociological study of those seeking resolution of health problems through hospital use. In part this may be because unlike chronic illness impairments, disability is not associated with a single physical difference (Grue, 2016). Here we have attempted to understand disabled people's experiences of everyday healthcare through the lens of barriers and threats to embodied well-being in hospital environments. Our article has explored how disabled people perceive hospital barriers as immediate threats to their embodied well-being, and the negotiation strategies these necessitate. These threats arise both from inside the body (Robertson, 2006) and outside the body (Imrie, 2012) and are often experienced through felt and enacted stigma, shame and blame (Scambler, 2009).

While the creation and consequence of barriers are seldom intended, they are nonetheless the products of both medial (for example, the behaviour of a health professional or an unavailable hoist) and distal (for example, building regulations and organisation of hospital services) influences on the disabled body. Not only do they threaten embodied well-being, but they also constrain negotiation opportunities and position disabled people in an antagonistic relationship to healthcare professionals and those who regulate hospital space. We consider our findings further in the context of barriers as environmental (space), organisational (policy and practice) and social (emotional), although note that these categories are not mutually exclusive.

Within hospital settings, the embodied experience of disabled people can be traced to the day-to-day management and regulation of the use of, and movement around, hospital space. It is recognised that patient need is subjugated to the work schedules and practices of multiple healthcare professionals, which are themselves bound in to power hierarchies and complex organisational structures (Frank, 1995). These schedules and practices are seldom designed to be responsive to the (non-medical) needs of disabled people (Abraham, 2011). Yet responsiveness could be made through a commitment to make timely adjustments, especially those that are inexpensive and within the competency of relatively junior personnel, for example, a healthcare assistant asked to locate a pressure relieving mattress or a maintenance person scheduled to lower a mirror to wheelchair height in a disabled toilet. However,

indifference to the expert knowledge that disabled people have of their needs can hamper adjustment making because the patient benefit is underrated and their simplicity misinterpreted as requiring a low priority. To counter this, care practices must incorporate respect for the lived experience of disabled people along with a commitment to identify both the medial and distal factors sustaining a particular barrier in order to highlight and rectify localised opportunities and obstacles to change.

What happens within hospitals is also the result of organisational forces that originate beyond it. This includes for example government policy, a domain too vast for detailed consideration here. However, one example apposite to our findings illustrates a discrepancy in concern for the embodied well-being of patients. For over a decade one idea has been for hospital design to be patient centred, in recognition that well-being is contingent upon the detail of the hospital environment, such as choice of colour schemes used (Douglas and Douglas, 2005). However, this commitment to patient centred design is at odds with our findings and those from other research (see, for example, Lawler et al., 2013), which describes how aspects of hospital design undermine the embodied well-being of disabled people. However, the policy itself illustrates the argument Smith (2012) makes that the normative body actualised through policy texts is an abstract one, devoid of any fleshy characteristics. This actualisation is resisted by the argument that barrier removal must enable a disabled person to 'function' in a hospital and to do so with the same degree of comfort, dignity and ease of movement as everyone else (Loja et al., 2013). To achieve a standard of design that enhances the well-being of all, including disabled people, requires transformation, one essential element of which would be a critique of architectural practice to expose impediments to creating building designs which meet the broadest possible range of user needs (Jones, 2014). In addition, that transformation requires an approach to the regulation of hospital space which maximises flexibility, both in terms of its use and the working practices that take place therein: this is necessary to meet individual needs (Winance, 2014). One impetus for such a transformation in the United Kingdom may come from NHS equality strategies which include the NHS Equality Delivery Service 2 (NHS England, 2013), a set of methodologies service providers must use to identify and reduce unjustified variations in use in each facility. However, while this methodology does emphasise the need to address equity of health outcomes for some populations, the issue of how barriers of the type explored here impact on health outcomes has received scant attention.

A common aim of health policy is equality of access (O'Brien, 2013). This requires the distribution of necessary resources to enable patients to utilise the appropriate healthcare facility in a timely manner and without undue agency. Research has identified that for disabled people, hospital attendance requires burdensome tasks, which range from the arrangement of assistance to trying to comprehend patient information in inaccessible formats (see, for example, Mele et al., 2005). These require self-efficacy, the development of which is mediated by socioeconomic status and personal characteristics such as age, ethnicity and gender (Allen, 2004; Shah and Priestly, 2001). Moreover, as argued above, barriers place disabled people in antagonistic relationships with healthcare professionals and raise real or anticipated social and emotional threats to both self and social identity. Disclosure of threats or their effects can be disempowering, especially when compounded by disablism (Thomas, 1999). We suggest that further research is needed to understand the connections between the tasks of attending appointments, the responsibility of

negotiating barriers, how these affect disabled people's health outcomes and their lower rates of satisfaction with healthcare (Allerton and Emerson, 2012).

Appreciating exactly how healthcare barriers are negotiated can contribute to understanding how the NHS might remove them. Equality legislation requires the NHS to incorporate the category 'disabled people' into its policy and practices, which has different implications from the more medicalised categorises used, such as 'long term conditions'. The latter denotes those needing regular treatment for a significant time, but gives no indication of the type of barrier he or she might face or any adjustments needed to ensure each appointment goes smoothly for all concerned. Perhaps existing good practices such as appointment letters that invite a patient to get in touch if they need a hoist to get on to an examination bed, or ward staff recognising the importance of allowing a personal assistant to stay with a disabled person, could be enhanced by the support of a hospital-based disability team to act as a resource for healthcare professionals and patients dealing with both current and anticipated barriers. Such an intervention would help address the fact that barriers in healthcare are impossible to predict, given the complexity of what is done in hospitals and the diversity of the patients.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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